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Administration on Developmental Disabilities

Administration for Children and Families • U.S. Department of Health and Human Services

Commissioner's Message



Commissioner's Forum

My first order of business in this issue of ADD Update must be to thank all those who showed even more determination than Mother Nature by coming out to attend the ADD Commissioner's Forum. Despite the snowstorm, the canceled flights, and the extreme cold 220 people were in attendance. That type of dedication on the part of the attendees is a tribute to the importance of the material we discussed.

The Forum was held February 18- 20, 2003 at the Mayflower Hotel, Washington, D.C. It began as scheduled on Tuesday night with a meeting to introduce the self-advocates in attendance. The contributions made by self-advocates are essential for ADD programs to remain in perspective, to maintain quality control, and to emphasize the various needs of individuals. Because individual input is so important I encourage those who were in attendance, and those who were unable to attend, to share with me their successes, lessons learned, suggestions, and materials through e-mail at pmorrissey@acf.hhs.gov.

My thanks go also our collaborating group the Developmental Disabilities Quality Coalition and to the Contractor's staff, all of whom worked hard to make the event successful.

Thanks to the many speakers and moderators who contributed their expertise, including Dr. Margaret Giannini, Director of the Office on Disability, U.S. Department of Health and Human Services, and keynote speaker Claude A. Allen, Deputy Secretary, U.S. Department of Health and Human Services. Mr. Allen's remarks were on the importance of the President's New Freedom initiative in planning for the future of ADD and what has been achieved already. Some of the figures he presented are as follows:

- Under the New Freedom Initiative, President Bush will propose a new \$1.75 billion over five years to help Americans with Disabilities transition from nursing homes or other institutions to living in the community
- New Freedom calls for a new spending total of \$2.1 billion over five years, \$417 million of that in fiscal year 2004 (FY04)
- A five year demonstration program that make the "money follow the individual" should receive \$350 million in FY04 to assist the states with their long term care systems
- Under the New Freedom Initiative, President Bush has proposed \$220 million over five years to fund projects that promote home and community-based care alternatives, \$11 million of that for FY04



- President Bush proposes \$95 million in spending over five years to extend Medicaid coverage to protect spouses of workers with disabilities, \$16 million of that in FY04
- Systems Change Grants have been proposed at \$40 million to support states in setting up new systems to support people with disabilities moving from institutions into the community.

The theme of the forum was **Building a Comprehensive Quality Management Program and Supporting the Direct Support Workforce for DD Service Systems**. My goals were to create some

real results from the forum by sending the attendees home with tools and information they did not have when they arrived and could put to work immediately at their own agency. Fostering relationships between peers and encouraging interaction helps agencies to set new goals, and plan continuous improvement. We often speak in terms of best practices, but occasionally forget that our efforts should not have an end point, they should evolve into new and better efforts.



Patricia A. Morrissey, Ph.D.
Commissioner
Administration on Developmental Disabilities

Program Progress

New Faces

New P&A and Council Executive Directors

There have been two changes in leadership in the Virginia Developmental Disabilities Network.

ADD welcomes V. Colleen Miller, Esq. as the first Executive Director of the Virginia Office for Protection and Advocacy (VOPA). VOPA became a newly independent agency on July 16, 2002 under a Virginia General Assembly initiative supported by Virginia's Governor Mark Warner. Colleen Miller formerly served as the Legal Director in the New Mexico Protection & Advocacy (P&A) system.

We also welcome Heidi Lawyer, the former Acting Executive Director of VOPA, as the new Executive Director of our Virginia State Council on Developmental Disabilities.

Our DD system is becoming only stronger and more viable by keeping experienced and valuable employees in the network. Congratulations to both of these Executive Directors!

Protection and Advocacy Agencies

Commissioner's Forum

Thank you to the Protection and Advocacy representatives in attendance at the Commissioner's Forum. Some P&A executive directors participated by presenting workshops and we will highlight their presentations here:

Project Title: "P&A Models for Quality Assurance to the Community"

Presenters: Lois Simpson, Executive Director, Advocacy Center, New Orleans, Louisiana
Kelly Bagby, Legal Director, University Legal Services, Washington, DC Tina Campanella,
Executive Director, The Quality Trust for Individuals with Disabilities, Washington, DC

Description: P&As are employing a variety of strategies to provide a system of protection to community residents. Two models have proven successful. The Louisiana P&A has developed a model of community ombudsmen who are available to visit community residents and identify problems. They have been successful in obtaining State funding to expand the project.

Washington, DC P&A, University legal Services (ULS), was involved in class action litigation that was ongoing when the expose in The Washington Post became public. ULS moved quickly to address this serious problem for DC residents and to address the negative publicity focused on community placements. As a result of the settlement agreement, the District Government agreed to develop a Community Trust fund at more then \$20 million to provide ongoing advocacy and monitoring of community programs throughout the District

Project Title: "Interagency Outreach Training Initiative: Collaboration to Promote Workforce Development"

Presenters: Marvin G. Fifield, Project Director, Center for Persons with Disabilities, Utah State University
Fraser Nelson, Executive Director, Utah Disability Law Center
Sarah Rule, Director, Center for Persons with Disabilities, Utah State University
Mark L. Smith, Director, Access Utah Network, Utah Governor's Council for People with Disabilities

Description: This is a collaborative, statewide effort that funds training projects to improve the quality of Utah's workforce of direct support professionals. Though the projects are funded on an annual basis, their collaborative impact is ongoing. The Initiative is intended ultimately to improve choices and independence for people with disabilities by supporting training for agency personnel and consumers. Interagency Outreach Training Initiative (IOTI) has three unique features:

1. The IOTI focuses on areas where critical gaps exist in training already offered within the State. These may result from policy shifts, new developments in technology, and recent disseminated effective practices. Consumers, family members, and providers participate in identifying these needs. Thus, training addresses the priorities and concerns of those who offer and those who participate in services and supports.
2. The IOTI promotes coordinated training across agencies. Identified gaps in training are generally experienced by multiple agencies. The IOTI operates through an interagency/interorganization Steering Council. Its members (consumers, family members, State agency staff and providers) define annual training priorities based upon commonly experienced needs, implement a competitive bid process to address them, and evaluate training project outcomes.
3. The IOTI promote innovative training. The Steering Council issues an annual request for proposals and funds only those with the most merit. Projects originate in a variety of

public and nonprofit agencies and organizations. Each must include an evaluation component and Project outcomes are reported annually.

Please contact these presenters for more information. ADD has received positive responses from participants that attended these sessions.

26th Annual Conference- P&A /CAP Training

Thanks to all the P&A Executive Directors who responded to a request for workshop topics for the 26th Annual Conference- P&A/CAP Training to be held May 28-31, 2003 at the Renaissance Hotel. The request was made so that the workshops chosen to be presented by Federal officials are the ones guided by you to make them responsive to your needs.

We encourage you to attend and send your staff and Board/Advisory council members. For the first time, at the suggestion of the board members, one-half of the day for the P&A Orientation will be geared to Board/Advisory council members. We are listening to concerns and are making decisions based on input received, to continue our partnership and our efforts to make life better for people with disabilities.

Training and Advocacy Support Center's New CEO/CEO Training

ADD is looking forward to participating in the Training and Advocacy Support Center's New CEO/CEO Training to be held in Albuquerque, New Mexico from April 8-11, 2003. This experience will be new to everyone in attendance. In addition to the two Federal partners from ADD and SAMHSA, Debbie Powell, ADD's Acting Deputy Commissioner, and Janice Davis, DD Team Leader, from our Dallas Regional Office will attend for the first time. The workshops will be geared to Federal orientation, Training and Technical Assistance contract and fiscal issues. We are planning for the sessions to be interactive. Come prepared with your questions and comments/suggestions. We highly encourage you to attend this training.

University Centers for Excellence in Developmental Disabilities Education, Research and Services

Connecticut

In October, 2002, a Real Choice Systems Change grant was awarded to the Connecticut Department of Social Services, and the **A.J. Pappanikou Center, UCEDD in Connecticut**, was selected to administer the grant. One of the goals of this grant is to assist three communities in Connecticut to become models of support for opportunities and choices for persons with disabilities across the lifespan. In January 2003 an opportunity was announced for elected town officials, legislators, and advocates to apply for their community to be a model for inclusive practices. As of February 28, a total of 43 municipalities had responded with requests for applications. Question & answer meetings will be held in March; the deadline for applications is April 18, with awards to be made by May 16.

The A.J. Pappanikou Center is pleased to announce the opening of the Center for Personnel Preparation in Early Intervention/Early Childhood Special Education, funded by the Office of Special Education Programs. The aim of the Center is to examine the current state of the nation in preservice and inservice training, certification/licensure, and supply and demand of all disciplines serving young children with disabilities and their families (birth to 5 years). A collaborative of the University of Connecticut, the University of Toledo, and Western Kentucky University, the Center will identify current trends and critical gaps in personnel preparation and provide recommendations to ensure an adequate supply of well-qualified personnel to serve infants, toddlers, and preschoolers with disabilities.

In collaboration with Connecticut's largest group of primary care physicians, **the A.J. Pappanikou Center** has developed a tracking tool to assist primary health care providers in monitoring infant and toddler hearing. This tool also provides a record of referrals for hearing screening and evaluation, as well as for early intervention. Testing of the effectiveness of the tracking tool to detect hearing loss earlier will begin in March, 2003. The tracking tool was developed through the "Enhanced Child Find Through Universal Newborn Hearing Screening" model demonstration project funded by the Office of Special Education Programs.

District of Columbia

The Georgetown University Center for Child & Human Development (GUCCHD), the UCEDD in DC, has been collaborating with the DC Superior Court, Family Division, for the past year. The UCEDD is providing an array of training, technical assistance, and consultation activities to support the DC Superior Court to implement the Family Court Act of 2001, as mandated by Congress. The DC Superior Court has named this system reform effort One Family, One Judge. The UCEDD assumed a major role in planning, implementing, and conducting the first city-wide conference entitled "Family Court Training Institute Partnerships for Change: Integrating Family Court and Service Systems," in collaboration with the Council for Court Excellence, funded by the Annie E. Casey Foundation, and the American Bar Association Center on Children and the Law. The Institute was convened on November 22, 2002, and more than 340 participants attended. This included judges, lawyers, and probation officers; family members, foster parents, and community-based organizations; staff from all child-serving agencies in DC government such as social workers, case managers, and other interdisciplinary personnel; representatives from DC Public Schools; Metropolitan Police Department; and others.

A significant number of children in the child welfare and juvenile justice systems have disabilities and live in poverty. Given this demographic picture, the UCEDD's contribution was as follows:

- Had a major role in conceptualizing and planning the event, modeled on system of care framework that includes principles of self-determination and cultural and linguistic competence.
- Recruited and supported family members to participate in the event.
- Identified and sponsored the keynote speaker and facilitated the five breakout sessions.

- Developed a comprehensive resource packet on laws, materials, definitions, best and proven practices, and other relevant information on serving people with developmental and other disabilities and their families.
- Exhibited and disseminated materials from the UCEDD and other major GUCCHD initiatives.
- Developed the evaluation and provided a summary report.

Virginia

Hand-Held Technology Project

On February 10, 2003, the **Partnership for People with Disabilities, the UCEDD at Virginia Commonwealth University**, launched a unique assistive technology project titled "Commonwealth Consortium on Hand-Held Technology." This project will research and test the application of hand-held computers/personal digital assistants in the lives of 50 individuals with autism, autism spectrum disorders, or traumatic brain injury. Outcomes will include the identification of alternative hand-held hardware and software applications, through actual real-life demonstrations with persons with severe disabilities in a variety of daily life experiences. The manager and lead researcher for the project is Tony Gentry, who worked most recently as a clinical specialist in the University of Virginia Medical Center, Departments of Neurology and Neurosurgery, and with the International Brain Injury Association as the Internet Education Content Director. He also was co-founder and program director of the John Jane Brain Injury Center of Martha Jefferson Hospital in Charlottesville, Virginia. The project is being funded by the Department of Rehabilitative Services.

Preparing IEP Booklet

The Partnership for People with Disabilities has produced a new booklet, "Preparing for My IEP." This easy and helpful booklet provides a simple and straightforward format for the student and IEP team members to use to gather and organize information for any IEP meeting. The booklet features helpful tools, including a copy of "Charting the Course," a graphic organizer for developing an IEP. To order this booklet (\$3.50), visit www.vcu.edu/partnership.

Vermont

Johnette Hartnett and Michael Collins, of **The Center on Disability and Community Inclusion, Vermont's UCEDD**, along with Tim Tremblay, of Vermont's Vocational Rehabilitation Division, have authored an article in the Fall 2002 Journal of *Vocational Rehabilitation* entitled "Longitudinal Outcomes In Vermont's Consumer Choice Demonstration Project (1993-1999)." This study explored strategies of providing service recipients with increased choice in the state vocational rehabilitation process.

The fourth and final manual of a series of paraeducator training manuals, "Supporting Students with Severe Disabilities," by Timothy Fox, has been completed and is available from the Center on Disability and Community Inclusion, Vermont's UCEDD (www.uvm.edu/~cdci/). This series is designed as an instructional curriculum, with Instructor's and Participants' Manuals that

include lesson plans, agendas, overheads, evaluations, and required readings. The series focuses on providing the most essential knowledge and skills necessary for paraeducators to begin their work in inclusive and collaborative classrooms for students with disabilities.

Policy Corner

Fiscal Year 2003 appropriations figures

(monies not yet available, as these figures are still being approved):

Title I - Developmental Disabilities Assistance and Bill of Rights Act of 2000

Councils \$71,134,600

P&As \$36,262,750

UCEDDs \$24,961,688

PNS \$12,402,854

Program Total \$144,761,892

Help America Vote Act of 2002

Voters with Disabilities \$15,000,000

Program Performance

Electronic Data System (EDS)

The FY 2002 Program Performance Reports for State Councils on Developmental Disabilities and Protection and Advocacy Agencies and FY 2003 Statements of Goals and Priorities (SGP) forms are being reviewed and locked-in. Once all the forms are locked-in, they will be available for viewing at Historical Forms section of the ADD's Extranet site (secured site).

Following are a few examples of **Quality Assurance** projects/activities from FY 2002 PPRs.

State Councils on Developmental Disabilities:

Florida:

The Florida Developmental Disabilities Council started a self-determination initiative by providing fiscal and technical assistance to a group of self-advocates to host the first statewide self-determination conference. 579 people attended the conference and at the end of the conference 11 individuals with developmental disabilities were elected to develop and lead a statewide self-determination organization. Another 100 people signed up to support self-determination initiatives in their local community.

The Council provided additional fiscal and technical assistance to the new statewide self-determination organization, Southern Movement for Independence, and for local chapter development. Additionally, the Council is supporting the second statewide conference to be held in August 2003.

Members of SMI are participating in the system redesign meetings for developmental disabilities program, writing letters and holding meetings with agency representatives to advocate for their issues. They also have developed a web site and publish a newsletter as other tools to forward their message.

Illinois:

In the early 1990's the Council supported the development of People First of Illinois and has maintained its support since that time. Self-sufficiency and independence are important values of People First and are supported by the Council. In an effort to assist People First to become organizationally sound, the Council provided technical assistance to this organization (as well as five other Council funded projects). Independence and self-sufficiency have been principles which guide People First in all that they do. For the past three years, as People First has diversified its funding, the Council has gradually reduced its financial support.

When Self Advocates Becoming Empowered began, the Council financially supported a key Illinois advocate to participate in organizational development meetings.

The Council continues its advocacy training for parents and for people with developmental disabilities. During the past year two new training projects were initiated. Both have goals to train people in advocacy and ensure that those individuals use what they learn to make a change in the supports and services they receive. The Council believes that people need to use what they learn in order to be successful.

During the previous fiscal year the Council undertook a major initiative known as the Illinois Lifespan Information and Advocacy Coordination project. The project, which is still underway, seeks to create a single resource that people can call or view online to locate the services they require. The idea is to provide information but also to coordinate services and connect people with local advocacy if they need additional support in their efforts.

State Protection and Advocacy System:

Arkansas:

ADD Collaboration Director's Forum on Quality was held. The Collaborative assisted in a survey assessing the needs of individuals on the home and community-based waiver (HCBW) in Arkansas and utilized the results of the survey in collaborative research about best practices.

Missouri:

P&A is participating in the Department of Mental Health Council on Quality Improvement, which is working to reduce abuse/neglect issues for DMH clients and to improve the department's response to incidents and ability to prevent abuse/neglect through the delivery of quality services.

New Jersey:

NJ P&A's Executive Director and Deputy Director discussed the findings of the community monitoring survey with the senior staff of the Division of Developmental Disabilities. Division

staff reported that they have established a new quality assurance unit, which will include as one of its major functions the monitoring of community programs.

Connecticut:

Connecticut received both a Nursing Facility Transitions Grant and a Real Choice Grant from the Centers for Medicaid and Medicare Services(CMS) in the U.S. Department of Health and Human Services. The goal of the Nursing Home Transitions Grant is to transition 150 individuals out of nursing homes and into community living arrangements. The Real Choice Grant is focused on building the capacity within the state to support informed decision making, independent living, and meaningful quality of life for persons with disabilities across the life span.

Upcoming Events & Announcements

Now Available

Publications

ADD Programs Brochure- The brochure presents overviews of ADD programs and statistical data.

ADD released the first issue of *ADD University Centers for Excellence in Developmental Disabilities Education, Research, and Service Highlights*. The booklet, which will be an annual ADD publication, is a companion piece to the SCDD and P&A booklets. The booklets are a look into promising practices, projects, and outcomes in ADD programs.

Reasonable requests for additional copies of all the above publications will be honored while supplies last, electronic copies are also available, please contact Nichole Dulin, ADD, ndulin@acf.hhs.gov.

ADDed Resources

The Department of Labor invites Nominations for the New Freedom Initiative Awards. The closing date for nominations is May 15, 2003. To view the press release, follow this link <http://www.acf.dhhs.gov/programs/add/pressrelease.doc>

The Application process for FY03 National Network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service has been posted on the ADD website at <http://www.acf.dhhs.gov/programs/add/UCEDD-03.htm>